## **PAPER**

# Efficiency of specialist rehabilitation in reducing dependency and costs of continuing care for adults with complex acquired brain injuries

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Received 4 June 2005 In revised form 24 September 2005 Accepted 23 November 2005 **Objectives:** To examine functional outcomes from a rehabilitation programme and to compare two methods for evaluating cost efficiency of rehabilitation in patients with severe complex disability. **Subjects and setting:** Two hundred and ninety seven consecutive admissions to a specialist inpatient rehabilitation unit following severe acquired brain injury.

**Methods:** Retrospective analysis of routinely collected data, including the Functional Independence Measure (FIM), Barthel Index, and Northwick Park Dependency Score and Care Needs Assessment (NPDS/NPCNA), which provides a generic estimation of dependency, care hours. and weekly cost of continuing care in the community. Patients were analysed in three groups according to dependency on admission: "low" (NPDS<10 (n=83)); "medium" (NPDS10-24 (n=112)); "high" (NPDS>24 (n=102)).

Results: Mean length of stay (LOS) 112 (SD 66) days. All groups showed significant reduction in dependency between admission and discharge on all measures (paired t tests: p<0.001). Mean reduction in "weekly cost of care" was greatest in the high dependency group at £639 per week (95% CI 488 to 789)), as compared with the medium (£323/week (95% CI 217 to 428)), and low (£111/week (95% CI 42 to 179)) dependency groups. Despite their longer LOS, time taken to offset the initial cost of rehabilitation was only 16.3 months in the high dependency group, compared with 21.5 months (medium dependency) and 38.8 months (low dependency). FIM efficiency (FIM gain/LOS) appeared greatest in the medium dependency group (0.25), compared with the low (0.17) and high (0.16) dependency groups. Conclusions: The NPDS/NPCNA detected changes in dependency potentially associated with substantial savings in the cost of ongoing care, especially in high dependency patients. Floor effects in responsiveness of the FIM may lead to underestimation of efficiency of rehabilitation in higher dependency patients.

Rehabilitation which helps an individual to improve their independence may be expected to reduce the long term cost of providing care for them in the community. However, for this process to be cost efficient, the initial investment in rehabilitation must be offset by the ongoing savings on care within a reasonably short timeframe. Given increasing constraints on healthcare funding, providers are under mounting pressure to demonstrate the value for money of rehabilitation programmes and to report data on cost efficiency as part of routine clinical practice. A number of methods have been developed to provide such data.

The Functional Independence Measure (FIM)\* is a standardised measure of independence in self care, which is widely used in the USA and in Europe to demonstrate the functional gains achieved by individuals during rehabilitation. In some insurance funded healthcare systems, reimbursement for rehabilitation is conditional on evidence of continued gain from serial FIM scores. Since the mid-1990s, "FIM efficiency" (calculated from FIM gain from admission to discharge/length of stay) has been used to benchmark the comparative efficiency of rehabilitation in different provider settings, and in different patient populations. <sup>1-3</sup> Large scale studies in people with acquired brain injuries<sup>4-5</sup> have equated points of FIM gain with saved minutes of care, and FIM efficiency has thus been applied as a surrogate marker for cost efficiency.

In the UK there has been less enthusiasm for this approach. This is partly because of concerns about the validity of mathematical manipulation of raw ordinal data, but also because of recognised floor and ceiling effects of the

FIM<sup>6 7</sup> which limit its use in some populations. For example, a very heavily dependent patient who progresses from needing help from two people for daily care, to needing only one person, may achieve a substantial reduction in the cost of continuing care, while changing very little on FIM rating. Similarly, an ambulant individual with severe cognitive deficits may achieve near maximum FIM scores, but nevertheless need around-the-clock care to ensure their safety. So although global disability measures such as the FIM and Barthel Index are shown to correlate with care needs on a population basis,<sup>5 8</sup> they cannot be used to assess them directly for a given individual.

The Northwick Park Dependency Score (NPDS)<sup>9</sup> and Care Needs Assessment (NPCNA),<sup>10</sup> <sup>11</sup> on the other hand, have been specifically designed to measure care needs in the more dependent groups, and to provide a generic estimation of care hours and weekly cost of care in the community on an individual basis. A recent survey of rehabilitation units in the UK has demonstrated growing uptake of this tool for assessing dependency in routine clinical practice.<sup>12</sup> If the cost of rehabilitation is known, and the savings in weekly cost of care estimated by the NPCNA, the time taken to offset the

**Abbreviations:** ABI, acquired brain injury; ADL, activities of daily living; FIM, Functional Independence Measure; LOS, length of stay; NPDS, Northwick Park Dependency Score; NPCNA, Northwick Park Care Needs Assessment

\*FIM is a trademark of the Uniform Data System for Medical Rehabilitation, a division of UB Foundation Activities, Inc. cost of rehabilitation may offer a more direct indicator of cost efficiency.

In both the UK and the USA, recent changes in the systems for reimbursement for healthcare services<sup>13</sup> <sup>14</sup> have raised fresh concerns in relation to funding for rehabilitation. The move towards a "standard tariff" for episodes of rehabilitation, regardless of dependency or length of stay, potentially disadvantages the most complex and dependent patients, because providers will be reluctant to bear the additional costs of their treatment. However, if rehabilitation is shown to be cost efficient for this group, in terms of reducing the cost of continuing care, then the case for providing adequately resourced rehabilitation for them is clearly strengthened. But which method should we use?

In this article we report a retrospective analysis of outcome data collected prospectively in the course of clinical practice for a cohort of patients with acquired brain injury (ABI) admitted to an inpatient rehabilitation service. We examine the cost efficiency of rehabilitation, as estimated by the NPCNA and the FIM, and compare their performance as indicators of value for money at different levels of dependency.

#### **METHODS**

The Regional Rehabilitation Unit at Northwick Park provides a tertiary specialist inpatient rehabilitation service for younger adults (mainly 16–65 years) with severe complex neurological disabilities—including physical, cognitive, behavioural, and/or communicative problems. The unit serves a wide catchment area in the South East of England to support people with complex rehabilitation needs that are beyond the scope of their local rehabilitation services. Since 1999 the team has recorded a battery of standardised outcome measures as part of routine clinical monitoring for all patients admitted to the unit. These include:

- The Functional Assessment Measure (UK FIM+FAM);<sup>15</sup> recorded within 10 days of admission and within five days of discharge by the multidisciplinary team. It includes the FIM (version 4.0<sup>†</sup>) comprising 13 motor and five cognitive items. The Barthel Index is derived through a validated algorithm.<sup>16</sup>
- The Northwick Park Dependency Scale (NPDS); recorded at fortnightly intervals for all patients by their named nurse. It is an ordinal scale of dependency on nursing time (number of helpers and time taken to assist with each task). There are two sections: (a) basic self-care needs and (b) special nursing needs.
- The Northwick Park Care Needs Assessment (NPCNA); derived from the NPDS by a computerised programme to provide a daily timetable of care needs. It estimates by calculation the "care hours per week" (RCH), and the

**Table 1** Demographic characteristics of the study population (n = 297)

Mean age	43.8 (SD 14.1)	years
Male/female ratio	2:1	
Mean length of stay	112 (SD 66) da	ys
Cause of brain injury	Number	%
Stroke: (71%)		
Cerebrovascular infarct	141	48
Cerebrovascular haemorrhage	68	23
Traumatic brain injury (19%)	58	19
Other: (10%)		
Inflammation/infection	16	5
Hypoxic brain injury	7	2
Tumour	6	2

approximate weekly "cost of care" (£/week), based on UK care agency rates.

The NPCNA provides a generic assessment of care needs, regardless of who provides and pays for them. The estimated cost of care is therefore independent of individual circumstances or local policy for the provision continuing care, which varies widely across the UK. Previous evaluations have demonstrated the reliability and validity of the NPDS and NPCNA° 10 and also sensitivity to change in those more dependent patients who fall below the floor of the FIM. 11

#### **Subjects**

Consecutive patients with ABI (of any cause) admitted to this service over a six year period from 1999–2005 were included. In view of limited staffing resources on the unit, a case mix policy is applied to limit the number of highly dependent patients at any one time. Patients are assessed before admission using the NPDS, and categorised into three groups on the waiting list, by their level of dependency.

- "Low" dependency (NPDS<10): patients in this group are largely self-caring, requiring only incidental help with activities of daily living (ADL). Typically admitted for short programmes of cognitive or behavioural rehabilitation.
- "Medium" dependency (NPDS = 10-24): patients generally require help from one person, for most ADL tasks.
- "High" dependency (NPDS≥25): patients require help from two or more people for most ADL tasks, and often also have special nursing needs.

#### Cost of admission

The service is funded through a "block" contract. Activity is reported to purchasers on a cost per case basis, according to the number of bed days used by each individual. The cost per bed-day for each year is calculated retrospectively (total contract sum/total bed-days used). In this series, the cost per bed-day varied from year to year. In 1999/2000 it was £225 per bed-day; £221<sup>‡</sup> in 2000/01, £256 in 2001/02, £281 in 2002/03, £325 in 2003/04, and in 2004/05. No differential costs were applied for the more dependent patients during the period of study, although these have subsequently been introduced. The cost of admission (bed-day cost × LOS) was calculated case by case, and the cost efficiency of rehabilitation was estimated from summary data in each of the three dependency groups (see footnote to table 3)

#### Data handling and analysis

NPDS, NPCNA, FIM, and Barthel Index data were extracted from the unit's database and transferred to SPSS version 11.5 (SPSS Inc, Chicago, IL, USA) for statistical analysis.

Most data were shown to be within acceptable limits for normal distribution (Kolmogorov-Smirnov p>0.05) with closely coinciding mean and median, so parametric tests were applied throughout for consistency  $^{\$}$ . Data were grouped by category of dependency on admission (see Subjects). Paired t tests were used to compare differences between admission and discharge within dependency groups. One way ANOVA tests were used to identify differences between

<sup>&</sup>lt;sup>†</sup>This older version of the FIM is applied only as part of the UK FIM+FAM with permission from the originators.

<sup>&</sup>lt;sup>‡</sup>The lower unit cost in 2000/01 was due to unusually high turnover bed turnover that year.

<sup>§</sup> An alternative analysis using non-parametric statistics gave similar results and is available on the journal website (see http://www.jnnp.com/supplemental).

Table 2	Mean scores on	admission	for the	different	dependency groups	,
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	Dependency group		
	Low (NPDS <10) (n = 83)	Medium (NPDS 10-24) (n = 112)	High (NPDS >25) (n = 102)
Age (years) (mean (SD))	41.8 (14.5)	45.8 (13.6)	43.4 (13.7)
Time since injury (months) (median (IQR))*	2.8 (1.7–4.6)	2.9 (1.7–4.2)	3.9 (2.4–6.8)
Scores on admission	Mean (SD)	Mean (SD)	Mean (SD)
NPDS score	4.7 (3.3)	17.0 (4.0)	39.6 (10.8)
NPCNA estimates			
RCH (care hours per week)	15.7 (9.3)	35.6 (6.9)	56.7 (11.7)
Cost of care (£/week)	£293 (303)	£877 (438)	£1868 (622)
FIM motor scale	74.7 (13.6)	58.7 (13.8)	29.7 (18.2)
FIM cognitive scale	27.8 (6.2)	24.9 (6.4)	17.9 (8.3)
FIM total	103.1 (15.9)	76.3 (16.3)	48.0 (23.6)
Barthel Index	16.1 (3.3)	9.7 (3.0)	5.2 (4.4)

\*Median (IQR) are given for time since injury because these data are significantly skewed.
FIM and Barthel Index are scores of "independence" (with higher scores reflecting less dependency), whereas the NPDS is a score of "dependency" (with higher scores reflecting greater dependency).

groups, and Bonferroni post hoc tests were used to compare each pair of groups. The relation between reduction in weekly cost of continuing care and change in NPDS, FIM, and Barthel score was examined using Pearson correlations.

#### **RESULTS**

Of a total of 387 admissions, 320 (83%) had acquired brain injury, of which NPDS/NPCNA data were available for n=311(97%) and FIM and BI data were available for n=297 (93%). The demographic characteristics of the study population (n=297) are shown in table 1. Eighty three patients were categorised as "low" dependency (NPDS<10), 112 "medium" (NPDS = 10–24), and 102 "high" dependency (NPDS  $\ge$ 25).

Table 2 shows the age, time since onset, and mean NPCNA, FIM, and Barthel Index scores on admission for each of the three dependency groups. Table 3 summarises the mean change in scores between admission and discharge for the three dependency groups. In all groups, NPDS, RCH, weekly cost of care, FIM, and Barthel Index scores all changed significantly from admission to discharge (paired t tests p<0.001). However, considerable heterogeneity was noted, especially in care hours and costs. Overall, 232 (78.1%) patients demonstrated a reduction of care needs between admission and discharge, 25 (8.4%) remained the same, and

35 (11.7%) patients actually showed increased care needs as the full extent of their cognitive and physical condition became clear.

One way ANOVA tests demonstrated significant overall differences between the dependency groups for change scores in all the parameters listed in table 4 (p<0.001). Group by group Bonferroni tests demonstrated significant differences in NPDS and reduction of cost of weekly continuing care between all groups. By contrast, the FIM and BI detected differences in change between the low and medium dependency groups, but not between the medium and high groups—confirming the floor effect in these scales.

The high dependency group had significantly longer lengths of stay than the medium and light groups—mean difference 50 (SE 8) and 84 (SE 8) days respectively (both p<0.001 on Bonferroni post hoc test). However, the NPDS and the NPCNA also showed significantly greater change in the high dependency group, so that the time to offset the cost of rehabilitation by savings in the weekly cost of care was actually lowest in the high dependency group (16.3 months), as opposed to 21.5 months for the medium, and 38.8 months for the low dependency groups (see table 2). Meanwhile, FIM efficiency appeared to be greatest in the medium dependency group (0.25) compared with 0.17 in the low and 0.16 in the high dependency groups.

**Table 3** Mean change in NPDS, NPCNA, FIM, and Barthel Index scores from admission to discharge and estimates of cost efficiency calculated for the group as a whole

	Dependency group		
	Low (NPDS < 10) (n = 83)	Medium (NPDS 10-24) (n = 112)	High (NPDS >25) (n = 102)
	Mean change (95% CI)	Mean change (95% CI)	Mean change (95% CI)
NPDS	-1.9 (-2.6  to  -1.1)	-8.2 (-9.5  to  -7.0)	-16.3 (-18.5 to -14.0)
NPCNA estimates			
RCH (care hours per week)	-7.5 ( $-9.6$ to $-5.2$ )	-13.6 ( $-16.2$ to $-11.0$ )	-16.0 (-18.9  to  -13.0)
Cost of care (£/week)	-£111 (-179  to  -42)	-£323 (-428  to  -217)	-£639 (-789 to -488)
FIM motor scale	9.7 (7.8 to 11.6)	22.3 (19.9 to 24.6)	20.7 (17.3 to 24.1)
FIM cognitive scale	2.2 (1.5 to 3.0)	3.6 (2.7 to 4.4)	5.0 (3.8 to 6.3)
FIM total	12.0 (9.7 to 14.2)	26.1 (23.6 to 28.7)	25.9 (21.9 to 29.9)
Barthel Index	2.8 (2.3 to 3.4)	6.2 (5.6 to 6.8)	5.6 (4.7 to 6.5)
	Mean (SD)	Mean (SD)	Mean (SD)
Length of stay (days)	71.2 (38.2)	104.0 (42.2)	155.9 (81.6)
Mean cost of admission	£17,226 (10,071)	£27,774 (16,915)	£41,782 (21,638)
Estimated efficiency based on summary data		•	
Time taken to offset the cost of rehabilitation*	38.8 months	21.5 months	16.3 months
FIM efficiency†	0.17	0.25	0.16

<sup>\*</sup>Time taken to offset the cost of rehabilitation by savings in cost of care was calculated from mean cost of admission/mean reduction in weekly cost of care from admission to discharge, as estimated by the NPCNA.

<sup>†</sup>FIM efficiency was calculated from the mean change in total FIM score from admission to discharge (or FIM gain)/length of stay (days).

Table 4	Bonferroni post hoc tests comparing differences in change scores between t	the
three de	endency groups	

Parameter	Group comparison	Mean difference (SE)	95% CI	p Value*
NPCNA: estimated cost of care (£/week)	Medium v low	-£211 (85)	-416 to -7.0	0.04
	High v medium	-£316 (80)	-510 to $-122$	< 0.001
NPDS	Medium v low	-6.4 (1.1)	-9.2 to $-3.6$	< 0.001
	High v medium	-8.0 (1.1)	-10.6 to $-5.4$	< 0.001
FIM total	Medium v low	14.1 (2.2)	8.7 to 19.6	< 0.001
	High v medium	0.3 (1.9)	-5.4 to $4.8$	1.000
FIM motor	Medium v low	12.6 (1.9)	7.8 to 17.2	< 0.001
	High v medium	1.6 (1.8)	-5.6 to $2.8$	1.000
FIM cognitive	Medium v low	1.3 (0.73)	-0.4 to $3.1$	0.19
· ·	High v medium	1.5 (0.70)	-4.6 to 1.0	0.10
Barthel Index	Medium v low	3.3 (0.5)	2.1 to 4.5	< 0.001
	High v medium	0.6 (0.5)	-1.7 to $0.61$	0.74

Table 5 shows the relation between estimated reduction in weekly cost of continuing care and change in NPDS, RCH, FIM, and Barthel Index scores for the different dependency groups. As might be expected, the estimated weekly care hours provides the closest relation, although the relation with NPDS scores is almost as good in the higher dependency groups. The Barthel and FIM show a poorer relation throughout.

Finally, we explored the impact of rehabilitation on the cost of continuing care for the most severely disabled patients who are likely to remain severely dependent for the rest of their lives. We examined the subgroup (n = 40) who still had NPDS score >25 at discharge. The mean estimated reduction in cost of weekly care for this subgroup was £243 (SD 786) per week, with a mean length of stay 157(SD 94) days. The mean cost of rehabilitation (£41,488 (SD 23,481)) would have been offset within 42.6 months which still represents substantial long term savings in the cost of care in a set of individuals whose mean age was 43.3 (SD 12) years and who would therefore be expected to survive for perhaps another 20–30 years. The FIM efficiency for this subgroup, however, was only 0.06.

#### **DISCUSSION**

The systematic application of standardised outcome measures to assess the impact of rehabilitation is widely advocated in published standards of good practice<sup>17</sup> and UK surveys demonstrate substantial commonality in the choice of outcome measures.<sup>18</sup> However, in contrast with countries which have established systems for centralised data collection, the resulting data rarely reach the public domain in the UK. It is hoped that this article may stimulate other centres to collate and publish their own data.

Maintaining complete data series as part of routine practice in a busy clinical setting presents a considerable challenge. Consistent application of outcome measures is found to be greatest where instruments are simple and timely to use, and where they are perceived to be of immediate clinical relevance. The FIM+FAM is scored by a multidisciplinary team and takes on average 25–30 minutes. In this series, missing FIM+FAM data, especially in the early part of the study period, reflected the additional burden of scoring. By contrast, the NPDS/NPCNA is simple and practical to use, taking about 3–5 minutes to complete by a nurse who knows the patient well. It is popular with the nursing staff, who report that it provides a good reflection of their levels of intervention. As a result, data collection for the NPDS/NPCNA was relatively complete.

Both the NPDS and the FIM demonstrated relatively few gains in the low dependency group in this study. This is to be expected because these more independent individuals are already largely self sufficient for activities of daily living. Instead, their goals for rehabilitation focus on societal participation. The suitability of inpatient rehabilitation is questionable for these individuals who may well have been better managed in community based programmes, had they been able to cope safely at home or had an appropriate community placement been available.

As would be anticipated, the FIM score demonstrated maximal change in the medium dependency group, where measurements clustered in the more responsive middle range of the scale. However, even in this group, it is notable that the FIM efficiency in this current series is very low in comparison with many of the large recent US series<sup>13 20</sup> where figures of 1.5–2.0 would be more typical, with LOS usually under 28 days. Our figures are consistent with a previous analysis from a very similar UK unit<sup>22</sup> which also noted floor and ceiling effects of the FIM and Barthel Index, and reported a mean FIM gain of 17 for a mean LOS 124 days (equating to overall FIM efficiency of 0.14). In addition to a possible difference in

**Table 5** Pearson correlations between change in NPDS, FIM, and Barthel scores and reduction in cost of continuing care in the different dependency groups

	Dependency group				
	Total (all scores) (n = 293)	Low (NPDS < 10) (n = 84)	Medium (NPDS 10-24) (n = 110)	High (NPDS >25 (n = 99)	
Instrument	Pearson (r)	Pearson (r)	Pearson (r)	Pearson (r)	
NPDS	0.65***	0.35***	0.59***	0.63***	
RCH	0.69***	0.69***	0.66***	0.69***	
FIM total	0.38***	0.17	0.24*	0.39**	
Barthel Index	0.41***	0.17	0.46***	0.40**	

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case mix, this discrepancy between the US and the UK experience is likely to reflect system related factors in the health and social services which include:

- 1. A dearth of community rehabilitation services in some areas so that a greater proportion of the rehabilitation process is conducted in inpatient settings.
- 2. A cultural philosophy in the UK health and social care system where the State is responsible for the safe discharge of patients, and some may wait several weeks or months for a suitable placement. During this time they may or may not make gains which would be better reflected on other scales such as the NPDS or quality of life measures.

We suggest that improved availability of community rehabilitation programmes and supported living schemes could help to improve efficiency and turnover in inpatient rehabilitation services.

The substantial proportion of highly dependent patients described in this study is relatively unusual and reflects the selective referral of more complex patients to this tertiary specialist regional service. Although the total FIM score did improve during admission for this group, it did not show change commensurate with the increased length of stay and therefore FIM efficiency was comparatively low. In rehabilitation settings funded on the basis of continued demonstration of change in FIM many of these patients would very possibly not receive treatment. Nevertheless, the NPDS and NPCNA provide evidence of clinically important and cost efficient gains in this group. In settings where health and social care are funded by separate bodies, however, savings in continuing care costs may not provide a strong incentive to fund rehabilitation if the benefits are accrued elsewhere. These findings also underline the importance of jointly funded health and social care programmes for individuals with severe long term disabilities.

There are a number of shortcomings in this study:

Firstly, the data presented are collected prospectively by treating clinicians in a clinical setting, and may be less reliable than data collected in formal research settings. However, all staff are trained in the application of the tools and our own data on reliability have been published elsewhere and shown to be adequate. This level of accuracy is probably as good as can be expected within the context of routine clinical care, and the data have the advantage of reflecting real life NHS practice.

Secondly, the FIM version 4.0 used in this study is not the latest FIM version, which is restricted under copyright terms. The data are not therefore strictly identical with the current UDS datasets. However, we believe there are no major structural differences between the two versions which would invalidate the comparisons made in this article.

Thirdly, the NPCNA estimates of continuing care costs are not true assessments as applied in health economic studies. On the other hand, the NPCNA has been in clinical use now for over seven years and is increasingly taken up in other settings, both in the UK and further afield. Follow up studies show its continued relevance and sensitivity to change after discharge from rehabilitation settings. 11 21 Experience demonstrates it to be neither overly generous nor mean in its estimates of care hours and costs, and there are no other validated tools which provide estimated care costs in this manner and which are simple enough for routine application in clinical practice.

Subject to these recognised limitations, the study is the first of its kind to demonstrate that rehabilitation may yet be cost efficient for the most severely disabled patients with ABI, and that it has the potential to generate substantial savings in the cost of continuing care in the community, even though they remain dependent on care from others. The study shows clear floor effects in responsiveness of the FIM

at high dependency, which may lead to failure to detect clinically and financially important gains as indicated by the NPDS and NPCNA. It emphasises the need for a range of different measures to detect meaningful change during rehabilitation in different patient groups and at different stages in the rehabilitation process.

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Competing interests: as employees of the NHS working within the Regional Rehabilitation Unit at the time the work was undertaken, the authors have a natural desire as professionals to ensure that the service is appropriately contracted for the nature of the work undertaken. Outcome measurement is a specific research interest of our centre. Both the NPDS, the NPCNA were developed through this department, but are disseminated free of charge. Professor Turner-Stokes is lead author on the papers which describe their initial development and validation, as well as that of the UK version of the FIM+FAM. However, none of the authors has any personal financial interests in the work undertaken or the findings reported.

Ethics approval: the Regional Rehabilitation Unit gathers this outcome data routinely in the course of clinical practice. Local research ethics committee permission has been obtained to report the data retrospectively for research and audit purposes.

#### **REFERENCES**

- Chae J, Zorowitz RD, Johnston MV. Functional outcome of hemorrhagic and nonhemorrhagic stroke patients after in-patient rehabilitation. Am J Phys Med Rehabil 1996;75:177–82.
- 2 Dombovy ML, Drew-Cates J, Serdans R. Recovery and rehabilitation following subarachnoid haemorrhage: Part II. Long-term follow-up. *Brain Inj* 1998:12:887-94.
- 3 Dombovy ML, Drew-Cates J, Serdans R. Recovery and rehabilitation following subarachnoid haemorrhage. Part I: Outcome after inpatient rehabilitation. Brain Inj 1998;12:443–54.
- 4 Granger CV, Cotter AC, Hamilton BB, et al. Functional assessment scales: A study of persons after stroke. Arch Phys Med Rehabil 1993;74:133–8.
- 5 Granger CV, Divan N, Fiedler RC. Functional assessment scales: A study of persons after traumatic brain injury. Am J Phys Med Rehabil 1995;74:107–13.
- 6 Streppel KR, Van Harten WH. The Functional Independence Measure used in a Dutch rehabilitating stroke population; a pilot study to assess progress. Int J Rehabil Res 2002;25:87–91.
- 7 van der Putten JJ, Hobart JC, Freeman JA, et al. Measuring change in disability after inpatient rehabilitation: comparison of the responsiveness of the Barthel Index and the Functional Independence Measure. J Neurol Neurosurg Psychiatry 1999;66:480–4.
- 8 Disler PB, Roy CW, Smith BP. Predicting hours of care needed. Arch Phys Med Rehabil 1993;74:139–43.
- 9 Turner-Stokes L, Tonge P, Nyein K, et al. The Northwick Park Dependency Score (NPDS): a measure of nursing dependency in rehabilitation. Clin Rehabil 1998:12:304–18.
- 10 Turner-Stokes L, Nyein K, Halliwell D. The Northwick Park Care Needs Assessment (NPCNA): a directly costable outcome measure in rehabilitation. Clin Rehabil 1999;13:253–67.
- 11 Nyein K, Turner-Stokes L, Robinson I. The Northwick Park Care Needs Assessment (NPCNA): A measure of community care needs: Sensitivity to change during rehabilitation. Clin Rehabil 1999;13:482–91.
- Skinner A, Turner-Stokes L. The use of standardised outcome measures for rehabilitation in the UK. *Clin Rehabil* 2005 (in press).
   Hoffman JM, Doctor JN, Chan L, *et al.* Potential impact of the new medicare
- 13 Hoffman JM, Doctor JN, Chan L, et al. Potential impact of the new medicar prospective payment system on reimbursement for traumatic brain injury inpatient rehabilitation. Arch Phys Med Rehabil 2003;84:1165–72.
- Department of Health. Reforming NHS Financial Flows: introducing payment by results. London: Department of Health, 2002.
   Turner-Stokes L, Nyein K, Turner-Stokes T, et al. The UK FIM+FAM:
- 15 Turner-Stokes L, Nyein K, Turner-Stokes T, et al. The UK FIM+FAM: development and evaluation. Functional Assessment Measure. Clin Rehabil 1999;13:277–87.

- 16 Nyein K, McMichael L, Turner-Stokes L. Can a Barthel score be derived from the FIM? Clin Rehabil 1999;13:56-63.
- 17 Turner-Stokes L, Williams H, Abraham R, et al. Clinical standards for inpatient specialist rehabilitation services in the UK. Clin Rehabil 2000;14:468-80.
- Turner-Stokes L, Turner-Stokes T. The use of standardized outcome measures in rehabilitation centres in the UK. Clin Rehabil 1997;11:306-13.
   Turner-Stokes L. Standardised outcome assessment in brain injury rehabilitation for younger adults. Disabil Rehabil 2002;24:383-9.
- 20 Burnett DM, Kolakowsky-Hayner SA, Slater D, et al. Ethnographic analysis of Phys Med Rehabil 2003;84:263–7.
- 21 Rusconi S, Turner-Stokes L. An evaluation of aftercare following discharge from a specialist in-patient rehabilitation service. Disabil Rehabi 2003·**25**·1281–8
- 22 **Edwards MJ**, McNeil JE, Greenwood RJ. Process and outcome during early inpatient rehabilitation after brain injury. Disability Rehabil 2003;25:405-10.

# HISTORICAL NOTE

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## Myxoedema and Sir William Withey Gull (1816–1890)

his is a brief history of hypothyroidism and the contribution of Sir William Withey Hypothyroidism and its complications provide many clinical puzzles for neurologists.

The thyroid had no known function until the end of the 19th century. In the wake of the term coined by Claude Bernard (1813-1878) in 1855, "internal secretion", and his concept of the milieu interieur, Sir William Withey Gull in 1873 was one of the first to understand that the cause of myxoedema is atrophy of the thyroid gland.

Gull's seminal paper<sup>1</sup> related the changed appearance of a Miss B:

"after the cessation of the catamenial period, became insensibly more and more languid, with general increase of bulk... Her face altering from oval to round, ...the tongue broad and thick, voice guttural, and the pronunciation as if the tongue were too large for the mouth (cretinoid)... In the cretinoid condition in adults which I have seen, the thyroid was not enlarged. ...

There had been a distinct change in the mental state. The mind, which had previously been active and inquisitive, assumed a gentle, placid indifference, corresponding to the muscular languor, but the intellect was unimpaired... The change in the skin is remarkable. The texture being peculiarly smooth and fine, and the complexion fair, at a first hasty glance there might be supposed to be a general slight oedema of it... The beautiful delicate rose-purple tint on the cheek is entirely different from what one sees in the bloated face of renal anasarca."

Four years later, William Miller Ord (1834-1902)2 introduced the term myxoedema. Like Graves' disease, it was generally considered an affliction of the nervous system, which shows how little was known of the thyroid. William Smith Greenfield (1846-1919) of Edinburgh, who examined pathologically one of Ord's myxoedema patients observed that it was the antithesis to exophthalmic goitre. In his Bradshaw Lecture (1893):

'In thus discussing Graves' disease, even provisionally as a disease of the thyroid gland rather than of the nervous system, I am aware that I am opposed to nearly all English and American physicians of eminence.'

but Kocher even 10 years later observed:

"Surgeons had simply assumed that the thyroid gland has no function whatever...";

And Jaques-Louis Reverdin asked in 1882:

"Can it be that the thyroid body whose functions are still obscure plays a part in haematopoiesis so important that its ablation produces such profound trouble?"

George Redmayne Murray(1865-1939) of Newcastle, stimulated by his mentor Victor Horsley (1857-1916), introduced in Britain the successful treatment of myxoedema in 1891, with injections of sheep thyroid extract.3 A similar success in Lisbon reported in 1890,4 but reported in Portuguese, was overlooked.

The discovery of autoimmune thyroid disease<sup>5 6</sup> had to await the 20th century.

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#### References

- Gull WW. On a cretinoid state supervening in adult life in women. Trans Clin Soc Lond, 1873-, 1874;7:180-185.
- 2 Ord WM. Report of a committee of the Clinical Society of London nominated December 14, 1883, to investigate the subject of myxoedema. Trans Clin Soc Lond 1888;21(supp).
- 3 Murray GR. Note on the treatment of myxoedema by hypodermic injections of an extract of the thyroid gland of a sheep. Brit Med J 1891;2:796.
- 4 Un cas de myxoedème traité par la greffe hypodermique du corps thyroïde d'un mouton. Sem Medicale 1890;10:294.
- 5 Weetman A. Autoimmune thyroiditis: predisposition and pathogenesis. Clin Endocrinol 1992;36:307-23
- 6 Vaidya B, Kendall-Taylor P, Pearce SHS. The genetics of autoimmune thyroid disease. J Clin Endocrinol Metab 2002;87:5385-5397